

Patient care plan information

Treatment of Ewing sarcoma at The Christie with irinotecan and temozolomide

Introduction

This information is for patients who are being treated in the medical oncology sarcoma clinic at The Christie for advanced Ewing sarcoma. This leaflet aims to cover the same information discussed in the clinic and will help you remember what was said.

Description of treatment with irinotecan and temozolomide for relapsed Ewing sarcoma

Patients are prescribed the following drugs:

- temozolomide is a capsule form of chemotherapy
- irinotecan is an intravenous (IV) chemotherapy.

Understanding how the treatment works

Both drugs destroy cancer cells. The chemotherapy goes into the blood stream and it reaches all parts of the body. It will reach the cancer cells wherever they are. If the cancer cells are sensitive to the drugs then they will die.

Expected benefits

The aim of treatment is to control the cancer by slowing it down or stopping it growing. Patients often feel better when they start the treatment; cancer symptoms will hopefully improve. The cancer deposits may shrink in size but this may take time and doesn't always happen. The important thing is to stop the cancer growing.

Success rate

Studies have shown that about 60% of patients benefit when treated with this therapy.

Duration of benefit

The effect on the cancer is not permanent. On average, the benefit a patient gets following treatment with irinotecan and temozolomide lasts about 9 months. For some patients the effect may last longer.



Risks and side effects

The side effects of temozolomide and irinotecan are described in more detail in a separate sheet we will give you. Briefly, the main ones are: nausea, sore mouth, tiredness, hair loss, rash and diarrhoea. Not everybody gets all the side effects. We will give you anti-sickness medication and other medicines can be given to help if you have other side effects.

Detailed description of care plan

Initial investigations

Before you start the treatment the following tests are usually needed: chest X-ray, heart tracing (ECG), routine blood tests (full blood count, kidney function, liver function, clotting screen).

We will normally review any outside biopsy or surgery specimens of your tumour (specialist sarcoma pathology review).

Ideally, you need to have had scans within 4 weeks of starting treatment.

You may want to think about having a central line (or central venous catheter) for this treatment. Your doctor will discuss this with you.

Description of treatment

Treatment can be given as a day case (you don't need to stay in hospital overnight).

Temozolomide capsules are taken for days 1 to 5. The capsules are available in different strengths, so your daily dose may be made up of more than one capsule.

The irinotecan is given as a 60-minute infusion (drip) on days 1 to 5 and 8 to 12. When the drip is finished you can go home each day. The treatment is given Monday to Friday for two weeks and then 1 or 2 weeks' break and then start again. Treatment can be continued for 6 to 8 cycles if you are coping with it well.

Other medication given alongside your chemotherapy

As well as your chemotherapy we will give you drugs to help with side effects.

For sickness / nausea: This chemotherapy does not usually make you feel or be very sick. When you go home you should have a supply of anti-sickness tablets to take with you. The usual dose is 1 cyclizine tablet every 8 hours (3 times a day).

Mouth care: You should use a soft tooth brush and a simple antiseptic mouth wash (for example, Chlorhexidine/Corsodyl) regularly if the mouth is not sore. If you get a sore mouth, you may find switching to baby toothpaste is more comfortable and a different painkilling mouthwash called Difflam.

Planned investigations and visit schedule

Once all the scans and blood test results have been completed and you have signed your consent form, treatment can usually start within about 10 days. Here is the usual visit schedule:

	Visit description
Mon	Blood tests & Medical review Day 1 temozolomide and irinotecan
Tues	Day 2 temozolomide and irinotecan
Weds	Medical review Day 3 temozolomide and irinotecan
Thurs	Day 4 temozolomide and irinotecan
Fri	Day 5 temozolomide and irinotecan
Mon	Blood tests & Medical review Day 8 irinotecan
Tues	Day 9 irinotecan
Weds	Medical review Day 10 irinotecan
Thurs	Day 11 irinotecan
Fri	Day 12 irinotecan
3rd week	No hospital appointments
	Re-start on Day 22 or Day 28

Scans and checking if the chemotherapy is working

You will have scans every 2 to 3 cycles (6-9 weeks) to check if the chemotherapy is working. It may be possible to get a preliminary report on the day of the scan or soon after but a proper report can take up to 2 weeks.

Do's and don'ts

General advice on do's and don'ts for cancer patients are in the booklet 'Chemotherapy: a guide for patients'.

Alternative treatments

This is our current preferred treatment for relapse. Other treatments that have been used in the past include topotecan and cyclophosphamide (a very similar chemotherapy drug which must be given as an inpatient).

Oral etoposide is also sometimes used. This is a tablet-only type of chemotherapy drug and does not involve as many visits to the hospital but is thought to have a lower chance of controlling the cancer.

Please note that you do not have to have any chemotherapy if you do not want to. Take time to decide what is right for you.

Access to treatments not available on the NHS

The treatment we offer within the NHS has been tested and shown to provide benefit to patients. The side effects of treatment are also known. If a treatment is not available within the NHS it may be because the evidence for benefit is not convincing or the evidence is not yet there.

New treatments are tested in clinical trials. The sarcoma team at The Christie is an active research team and if there is a clinical trial open that would be suitable for you. We will discuss this with you.

Under new regulations from the Government, patients now have a right to pay for treatments that are not available within the NHS. If there are any treatments like this we will discuss them with you.

Responsibilities – who does what

The Christie team: Dr Leahy and the sarcoma team at The Christie will be responsible for supervising your cancer treatment. This will include prescribing the chemotherapy and the other associated medications along with arranging all the tests and scans described above. As well as the treatment itself, we will do our best to support you through your illness including help with managing your symptoms and answering your questions.

Your GP: Although the specialist team may be the main focus of care while you are on this care plan, your GP and their team still have an important part to play. We will be sending updates to your GP after each visit to The Christie so they are fully informed about what is happening.

Community palliative care support: All patients with a diagnosis of advanced cancer are entitled to referral to the community palliative care nurse team in their area. We recommend you take advantage of this now even if you are feeling generally well. They offer a range of services which varies slightly from area to area, and we suggest you discuss this with your GP.

Other specialist teams: If you are also under the care of other hospital teams then you should continue to attend your appointments with them unless advised otherwise. Please provide contact details (for example, consultant name and hospital) and we can add them to the list of doctors who receive updates about you.

Other information available

The following other information is available that you may be interested in:

Chemotherapy: a guide for patients and their carers

Irinotecan and temozolomide drug information

You can visit the cancer information centre (department 3), call on **0161 446 8100** or drop in Monday to Friday 10:00am – 4:00pm

Contacts

Consultant: Dr Michael Leahy

Dr Leahy's secretary: Mrs Gwyn Mattimore, telephone **0161 446 8384**

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.



Contact The Christie Hotline for
urgent support and specialist advice
The Christie Hotline: 0161 446 3658
Open 24 hours a day, 7 days a week